

INSTITUTE OF MEDICINE

Real People
Real Problems:

An Evaluation of the
Long-Term Care
Ombudsman Programs
of the Older Americans Act

1995



SUMMARY

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An Evaluation of the
Long-Term Care Ombudsman Programs
of the Older Americans Act

Division of Health Care Services

INSTITUTE OF MEDICINE

Jo Harris-Wehling, Jill C. Feasley, and
Carroll L. Estes, *Editors*

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The image adopted as a logotype by the Institute of Medicine is based on a relief carving from ancient Greece, now held by the Staatlichemuseum in Berlin.

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LONG-TERM CARE OMBUDSMAN PROGRAMS**

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Preface

The subject of this study, the long-term care (LTC) ombudsman programs, came about two decades ago in response to the widespread perception that there was a crisis in nursing home quality. Despite laws and regulations to address these concerns and to protect nursing home residents, scandals involving poor and negligent care were surfacing. The mission of the ombudsman program was twofold: while advocating for broad policy changes, ombudsmen were to help resolve the very real problems faced by real people in nursing facilities. In 1981, the program's mission was extended to cover the concerns of residents of board and care facilities.

Over the past two decades, quality assurance activities for nursing facilities have multiplied. In particular, a 1986 Institute of Medicine study, *Improving the Quality of Care in Nursing Homes*, made far-reaching recommendations for federal policy in this area. As a result of that study and subsequent legislation in 1987, several policies have been adopted to address problems in nursing home quality. Phasing in these changes is a slow and lengthy process that is far from complete. Although ombudsmen do not bear the responsibility of implementing these changes, much of their activity for the past decade has been concerned with and shaped by the anticipation, inception, and implementation of these new laws and regulatory reforms.

In the early 1990s, policymakers-at the urging of ombudsmen themselves-concluded that an in-depth examination of the program was warranted to examine its present strengths and weaknesses and assess its potential for future contributions. The Congress of the United States directed the Assistant Secretary for Aging of the Administration on Aging (AoA) to conduct a study of the state LTC ombudsman programs. AoA subsequently contracted with the Institute of Medicine to perform the study.

The effectiveness of the current program is not well understood, and its potential for having a meaningful impact beyond the relatively narrow settings of LTC facilities is not known. Nevertheless, the program serves as a model for several proposed “health care ombudsman” programs. Consequently, many experts and parties interested in the LTC arena, as well as those concerned more broadly with comprehensive health care reform, will look to this study for guidance. Can the structure, activities, and accomplishments of the present LTC ombudsman program be successfully generalized to other settings, populations, and challenges?

This report is the culmination of a 12-month effort by a committee of 16 individuals recognized for their expertise in LTC, medicine, medical sociology, health care policy and research, clinical research, health law, health care administration, state government policy and program administration, consumer advocacy, public health, voluntarism, and the LTC ombudsman program. The charge to this committee was to assess the LTC ombudsman programs’ performance and, when appropriate, to make recommendations on public policy strategies by which the program can better achieve its objectives.

The committee engaged in several factfinding activities, including: site visits to six states; seven commissioned papers; structured, systematic contacts with directors of state units on aging, state and local LTC ombudsmen, LTC physicians, and grassroots advocacy groups; a one-day invitational symposium; a public hearing; two “open-mike” sessions at national professional conferences; discussions with four national associations of LTC facility providers; and a technical panel that was convened twice and called upon as needed throughout the course of the study.

The committee concluded that the ombudsman program serves a vital public purpose and merits continuation with its present mandate. Through advocacy efforts at both the individual resident and the system levels, paid and volunteer ombudsmen uniquely contribute to the well-being of LTC residents—complementing, but not duplicating, the contributions of regulatory agencies, families, community-based organizations, and providers. To **underscore this commitment** to the mission of the program, the committee sets forth several recommendations that are intended to bring the programs in compliance with the legislated mandates; build a nationwide database on key structure, process, and outcomes measures for the program; enhance each state’s ability to operate a unified statewide **Office** of the LTC Ombudsman; stimulate and guide needed research; and encourage leadership from the federal government.

The committee conjectured about the future of the ombudsman program in light of the health care reform movement and recent trends in health care and LTC. For more than a decade, virtually all components of the health care delivery system have undergone restructuring and have experienced the “ripple” or “domino” effects of Medicare and other policy changes. The

process of change holds significant clues about the future direction of health care and implications for the LTC ombudsman program.

The increasing growth and dominance of managed care organizations raise complex issues for LTC. Among the more pressing are: the relationship of LTC facilities and services to managed care organizations, how cost-containment strategies will be implemented in LTC settings, and how they will influence the organization, scope, and delivery of care. Additionally, the nature and scope of community-based service delivery has altered to such an extent that traditional conceptions of post-hospital care and LTC are no longer realistic. Average lengths of stay in nursing homes are decreasing and the nursing home is shifting in some respects from a long-term residence to a sub-acute facility. The home care sector is experiencing considerable growth, attributable in part to advances in medical technology that have led to the transfer of “high-tech” medical procedures from hospitals, clinics, and nursing facilities to the home setting.

Increased demand for ombudsman-type services will likely rise as managed care and cost-containment strategies play a more prominent role in decision making about who **does**—or does not—enter nursing facilities and other LTC facilities, and as more LTC services are provided in home- and community-based settings. If the ombudsman of the future serves only residents of LTC facilities, many vulnerable persons needing the services offered by an ombudsman will be denied access. The extent to which the LTC ombudsman program is poised for integration into the frameworks of the larger, restructured health care system and coordinated with other forms of consumer advocacy depends in part on how successfully the present program fulfills its mission. The committee’s recommendations are intended to strengthen the program’s capacity to carry forth with its current mission and prepare for the real problems that will be faced by real people in the future.

Carroll L. Estes
Chair



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The Committee to Evaluate the State Long-Term Care Ombudsman Programs of the Older Americans Act would like to acknowledge the assistance that they and the study staff received from several individuals and groups during this study.

The study was funded by the Administration on Aging (AoA) of the Department of Health and Human Services (DHHS). AoA staff members-William Benson, Saadia Greenberg, Jack McCarthy, Michio Suzuki (deceased October 1994), and Sue Wheaton-helped keep the committee and staff informed of relevant activities, facilitated contacts with the printer of the committee's report, and provided useful background material on the ombudsman program. James Steen served as the study's project officer until mid-January 1994; Nancy Wartow served in that capacity thereafter. Staff in several regional offices of the AoA and the DHHS Office of the Inspector General provided background information for the study.

We are indebted to several hundred individuals in the six states visited by the committee (California, Colorado, Florida, Massachusetts, Minnesota, and Virginia) who welcomed the committee graciously into their communities and shared their thoughts, experiences, and time. On each visit, the committee met with state, local, and volunteer ombudsmen, residents and staff of nursing facilities and board and care homes, state officials, and advocates. The committee appreciates the efforts of several individuals who provided testimony at the study's public hearing: Pat Nuckols, Beth O'Neill, Mercedes Patterson, Mary Sapp, and John Willis. We also express our gratitude to the many active state and local long-term care (LTC) ombudsmen, both paid and volunteer, and former ombudsmen for participating in our study. Additionally,

the committee is grateful to the state unit on aging directors who contributed to the study.

The committee expresses its appreciation to the individuals who contributed to the committee's symposium in February 1994: William Benson, Sara Best, Albert Buford, Meredith Cote, Curtis Decker, Virginia Dize, Barbara Frank, Iris Freeman, Marshall Kapp, John Newmann, Patricia Riley, Michael Schuster, Carol Scott, and Bruce Vladeck. More than 75 people attended the symposium, and the committee benefitted from their questions and comments.

The committee received helpful contributions from many other experts and interested parties. We are indebted to the authors of the commissioned papers prepared for this study, which were used extensively by the staff and committee in their deliberations and in drafting this report; all are cited in the references. They include: Martha Holstein, Roland Hombostel, Ruth Huber, James Kautz, Deborah Lower, Richard Lusky and colleagues, and Charles Phillips and colleagues. The following representatives of national associations also provided valuable information and assistance at one committee meeting: Shawn Bloom, George Cate, Carol Fisk, Louis Iovieno, Evvie Munley, Janet Myder, Susan Pettey, and Ronald Retzke. Philip Lee provided inspiring comments at the committee's first meeting and Arthur Flemming honored us with his presence at our last meeting. We are especially indebted to Dr. Flemming for his comments about "real people with real problems," thereby providing the title for our study's report.

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Contents

SUMMARY

Origins of the Study and Report,	2
The Long-Term Care Ombudsman Program,	3
State Compliance with Program Mandates,	4
Findings,	4
Recommendations on Compliance,	6
Conflicts of Interest,	8
Legislative and Conceptual Aspects,	8
Recommendations on Conflicts of Interest,	9
Effectiveness of the Ombudsman Program,	11
Continuance of the Ombudsman Program,	11
Exemplary Practices and Performance,	12
Data and Information Systems,	13
Research Imperatives,	15
Adequate Management of Volunteers,	16
Adequacy of Resources,	17
Financial Resources and Program Performance,	17
Formula for Allocating Federal Funds and Level of State Contributions,	18
Management of Fiscal Resources,	19
Unmet Need and Unfunded Responsibilities,	20
Need for and Feasibility of Expanding the Ombudsman Program,	21
Closing Comments,	23

**The contents of the entire report,
from which this Summary is extracted,
are listed below.**

1 ADVOCATING FOR QUALITY OF CARE AND QUALITY OF LIFE FOR RESIDENTS OF LONG-TERM CARE FACILITIES	25
Introduction, 25	
What is Long Term Care?, 26	
Who Uses Long Term Care?, 27	
Nursing Facility Residents, 27	
Residents of Board and Care Homes and Other Residential Settings, 29	
Long-Term Care Expenditures and Sources of Funds: Who Pays?, 32	
Quality of Care and Quality of Life, 33	
Quality of Care, 33	
Quality of Life, 35	
Assuring, Assessing, and Improving Quality, 36	
The Institute of Medicine Study, 38	
Organization of this Report, 39	
2 OVERVIEW OF THE OLDER AMERICANS ACT LONG-TERM CARE OMBUDSMAN PROGRAM	41
Evolution of the Long-Term Care Ombudsman Program, 42	
Ombudsman Theory and Practice, 42	
History of the Long-Term Care Ombudsman Program, 43	
Status of the Current Program, 45	
Organizational Placement, 46	
Operation, 46	
Target Population, 53	
Human Resources, 53	
Funding, 58	
Functions of the Long-Term Care Ombudsman Program, 62	
Resident-Level Advocacy, 62	
Systems-Level Advocacy, 72	
Summary, 76	

3 STATE COMPLIANCE IN CARRYING OUT THE LONG-TERM CARE OMBUDSMAN PROGRAMS	79
Introduction, 79	
Compliance with Mandated Federal Provisions, 79	
Extent of Compliance, 80	
Direct Individual Advocacy Services, 80	
Systemic Advocacy, 86	
Factors that Enhance or Impede Compliance with the Program's	
Federal Mandates, 88	
Leadership Within the Organizational Framework, 88	
Elements of Infrastructure, 93	
Institutional Care Context, 96	
Summary, 98	
4 CONFLICTS OF INTEREST	101
Introduction, 101	
Legislative and Conceptual Aspects of Conflict of Interest, 102	
Older Americans Act Provisions on Conflict of Interest, 102	
Definitions and Conceptual Variations, 104	
Types of Conflict of Interest for the Ombudsman Programs, 108	
Amelioration of Individual Conflict of Interest, 119	
Conclusions and Recommendations, 121	
Summary, 126	
5 EFFECTIVENESS OF THE STATE LONG-TERM CARE OMBUDSMAN PROGRAMS	129
Introduction, 129	
Evaluation Context, 130	
Evaluation Strategy: Formative and Summative Evaluations, 130	
Effectiveness Questions, 131	
Data and Information Sources, 132	
Quality as a Central Issue in Effectiveness, 133	
Political and Environmental Factors Relevant to Effectiveness, 134	
Models of Implementation and Measures of Effectiveness, 135	
Infrastructure and Function, 135	
Performance Indicators, 138	
Effectiveness of the Ombudsman Program: The Data, 139	
Findings Related to Effectiveness, 141	
Barriers to Effectiveness, 147	
Committee Reflections on Data, 151	
Conclusions and Recommendations, 152	
Continuance of the Ombudsman Program, 152	

Exemplary Practices and Performance, 154	
Research Imperatives, 159	
Summary, 161	
6 ADEQUACY OF RESOURCES	185
Adequate Program Performance, 186	
Financial Resources, 189	
Financial Resources and Program Performance, 192	
Conclusions and Recommendations, 193	
Adequacy of Resources for the Currently Mandated Program, 193	
Funding Allocation Formula, 196	
State Match of Federal Funding, 198	
Fiscal Accountability for Ombudsman Program Budgets at the State and Local Levels, 199	
Unmet Need and Unfunded Responsibilities, 201	
Summary, 202	
7 EXPANSION OF THE LONG-TERM CARE OMBUDSMAN PROGRAM	205
Need for Ombudsmen Services by Consumers of Health Care and Long-Term Care Services, 206	
Vulnerable Populations, 208	
Complex Systems, 209	
Advocates for Vulnerable Populations, 211	
State Experience with an Expanded Ombudsman Program, 216	
Feasibility of Expanding the Current Long-Term Care Ombudsman Program, 218	
Conceptual Considerations, 218	
Operational Considerations, 223	
Conclusions and Recommendations, 226	
Summary, 229	
8 CLOSING COMMENTS	231
The Current View of the Long-Term Care Ombudsman Program, 231	
Visions of the Future: Changes that May Affect the Ombudsman Program, 232	
Regarding the Configuration of Long Term Care, 232	
Regarding the Role of the Ombudsman, 234	
Goals Revisited, 234	
REFERENCES	237

APPENDIXES

A	Older Americans Act: A Staff Summary (A Publication of the Select Committee on Aging)	251
B	Title VII-Allotments for Vulnerable Elder Rights Protection Activities: Chapter 2	261
C	Study Activities	269
D	Biographies of Committee Members	281
GLOSSARY AND ACRONYMS		289

TABLES AND FIGURES

Tables

2.1	Organizational Placement and Operation of the Long-Term Care Ombudsman Programs, by State, 47
2.2	Number of Nursing Home and Board and Care Home Beds, by State, 1992, 54
2.3	Long-Term Care Ombudsman Human Resources, Paid Staff and Volunteers, by State, 56
2.4	Long-Term Care Ombudsman Programs' Amounts of Funding by Source, FY 1993, by State, 60
2.5	Visitation Standards, by State, 64
2.6	Long-Term Care Ombudsman Complaints per 1,000 Beds, by State, 67
4.1	Statement on Conflicts of Interest of the National Association of State Long-Term Care Ombudsman Programs, 106
5.1	Examples of Performance Indicators for Ombudsman Programs, Three Domains, 140
5.2	Structure of the Office of the State LTC Ombudsman and Elements of the Host Agency(s) for the State and Local Entities, 162
5.3	Qualifications of Representatives of the Office, 164
5.4	Legal Authority, 166
5.5a	Resources: Financial, 169
5.5b	Resources: Information Management, 171
5.5c	Resources: Legal, 173
5.5d	Resources: Human, 175
5.6	Office of the State Long-Term Care Ombudsman Program, 177
5.7	Individual Resident Advocacy Services, 178
5.8	Systemic Advocacy Work, 180
5.9	Educational Services, 183

- 6.1 Fiscal, Staffing, and Long-Term Care Bed Data, Selected States, 188
- 6.2 Summary of Total Funding for the State Long-Term Care Ombudsman Programs, by State, FY 1993, 190

Figures

- 2.1 Sources of ombudsman funding, fiscal year 1993, 59
- 7.1 Relationship of the individual's lack of empowerment and the system's complexity to the individual's need for advocacy, 206

Summary

Long-term care (LTC) ombudsmen¹ advocate to protect the health, safety, welfare, and rights of the institutionalized elderly in nursing facilities* and board and care (B&C) homes. Given the dramatic changes that are occurring in the entire LTC sector, the need for such advocates is compelling. A multiplicity of factors-sociodemographic, economic, political, and clinical-are converging in ways that call for significant attention to the quality-of-care and quality-of-life needs of all persons needing LTC services.

“LTC services” is a broad term that describes a constellation of services used by people with disabilities to achieve a meaningful life according to their own expectations and yardsticks. These services include health care, social services, housing, transportation, and other supportive services. Typically, LTC is associated with the elderly, although many older persons never require such care and many who are not elderly do require LTC services. Elderly residents of LTC facilities (nursing facilities, B&C homes, and other group residential homes) are the designated constituency of ombudsmen.

¹The term “ombudsmen” carries no meaning with respect to the gender of the occupant of the position. Indeed, in the United States, the vast majority of long-term care ombudsmen are women.

²In this report “nursing facility,” the technical term for a Medicaid-certified nursing facility, is used more broadly to describe any nursing home-whether or not it is Medicaid-certified, Medicare-certified, or private-pay.

ORIGINS OF THE STUDY AND REPORT

This report from the Institute of Medicine (IOM) addresses important aspects of the LTC ombudsman program—specifically the LTC ombudsmen’s ability to deal with problems that affect the care provided to and the quality of life achieved by elderly residents of LTC facilities. The ombudsman program arose in response to the widespread perception of problems in nursing facility quality. The program began in 1972 through five state demonstration projects that were funded by the Department of Health, Education, and Welfare’s Health Services and Mental Health Administration. The Administration on Aging (AoA) received responsibility for the program during a departmental reorganization in 1973 and has retained that responsibility over the past two decades.

Recently, policymakers—at the urging of ombudsmen **themselves**—concluded that a more in-depth examination of the program is warranted, with the aim of clarifying present strengths and weaknesses and assessing the program’s potential for future contributions. To this end, the Congress of the United States directed, in the 1992 reauthorization of the Older Americans Act (OAA), that the Assistant Secretary for Aging conduct a study of the state LTC ombudsman programs. Through a contractual arrangement, the IOM carried out the study.

This report is the culmination of that work, which commenced in October 1993. To conduct the study, the IOM appointed a **16-member** expert committee comprising individuals recognized for their expertise in LTC, medicine, medical sociology, health care policy and research, clinical research, health law, health care administration, state government policy and program administration, consumer advocacy, public health, voluntarism, and the LTC ombudsman program (for details of committee members’ backgrounds and specialties, see Appendix D).

The committee’s report examines four key issues:

1. the extent of compliance with the program’s federal mandates, including conflict of interest issues;
2. the availability of, unmet need for, and effectiveness of the ombudsman program for residents of LTC facilities;
3. the adequacy of federal and other resources available to operate the programs; and
4. **the need for and feasibility of providing ombudsman services to older individuals who are not residing in LTC facilities.**

To inform itself on issues pertaining to this charge, the committee engaged in a variety of factfinding activities. These included site visits, seven commissioned papers, numerous contacts with a wide array of ombudsmen and

individuals with whom they interact, a one-day invitational symposium, and two meetings of a technical panel.

THE LONG-TERM CARE OMBUDSMAN PROGRAM

Concerns with the quality of nursing facilities, the care provided in them, and the government's ability to enforce regulations in them led to the creation of the LTC ombudsman program in the early 1970s. In contrast to regulators, whose role is to apply laws and regulations, ombudsmen are supposed to help identify and resolve problems on behalf of residents in order to improve their overall well-being. The ombudsman program works alongside other programs, groups, and individuals engaged also in efforts to improve the quality of care and quality of life of residents in LTC facilities.

Although the classic model of the ombudsman stresses neutrality and mediation, the role of the LTC ombudsman is considered a hybrid, since it was designed to encompass both active advocacy and representation of residents' interests over those of other parties involved. Additionally, in the classic model the ombudsman intervenes between the government and individual citizens. In the case of the LTC ombudsman program, however, intervention usually also includes a private third party—the nursing or B&C facility.

Today the LTC ombudsman program operates in all 50 states, the District of Columbia, and Puerto Rico. No single model can accurately describe these multifaceted programs. Variability in organizational placement, program operation, funding, and utilization of human resources has given rise to at least 52 distinctive approaches to implementing the program. The Office of the State LTC Ombudsman program is most often housed within the state unit on aging (SUA); 42 states have this arrangement. The SUAs in these states themselves vary in their organizational placement: some are housed in independent, single-purpose agencies; some reside in larger, “umbrella” agencies in which several other agencies report to a head office. Others are housed in independent state-run ombudsman agencies. Some even operate completely outside state government. Recent estimates of LTC ombudsman staffing put the number of full-time equivalent (FTE) paid staff at about 865. Volunteer ombudsmen number about 6,750, excluding volunteers who serve chiefly on advisory committees.

Funding for LTC ombudsman programs is patched together from multiple sources at the federal, state, and local levels. Most federal funding comes from the OAA. Sources for other funding include state and local governments, area agencies on aging (AAAs), the United Way, and foundations.

The primary activity required of LTC ombudsmen by the OAA is the identification, investigation, and resolution of individual complaints relating to

the residents of LTC facilities. The program clearly performs this function. In 1993, LTC ombudsmen received more than 197,800 complaints, lodged by more than 154,400 people.

Ombudsmen are required to address and attempt to rectify the broader, or underlying, causes of problems for residents of LTC facilities. When working on the systemic level, ombudsmen's responsibility to advocate for policy change includes evaluating laws and regulations, providing education to the public and facility staff, disseminating program data, and promoting the development of citizen organizations and resident and family councils.

STATE COMPLIANCE WITH PROGRAM MANDATES

If a state is operating a LTC ombudsman program in compliance with congressional mandates, the program will perform several functions. For purposes of reviewing the extent of compliance, the committee collapsed the several statutory functions of the LTC ombudsman program into two primary services: (1) direct, individual advocacy services, which should be accessible, available, and meet the needs of residents of nursing and B&C facilities, and (2) systemic advocacy services.

Findings

Although in some states and locales elements of the ombudsman programs are vigorously implemented, the ombudsman program as a whole has not been fully implemented with regard to the provisions of the OAA that call for ombudsman services to be available and accessible to residents of LTC facilities. The committee finds the following:

- Not all residents of LTC facilities in need of advocacy assistance have meaningful access to the services of an ombudsman.
- Given the lack of a frequent visitation pattern to LTC facilities by ombudsmen in many parts of the country and little, if any, evidence that other methods are used effectively to build an awareness in the community of the availability of ombudsman services, large numbers of residents of LTC facilities are unaware of, and thus would probably not be able to use, the ombudsman programs' services.
- For the most part, ombudsmen provide timely responses to complaints. However, serious problems exist in some locales. For example, some state programs serve a large proportion of their LTC residents largely through one central toll-free telephone service. In such cases, it is not unusual for ombudsmen to investigate complaints through telephone inquiries only.

Those residents most in need of an ombudsman to assist in protecting their health, safety, welfare, and rights may be reluctant or simply unable to initiate complaints to the ombudsman by such means as telephone calls because they are too frail or cognitively impaired.

- Implementation of the ombudsman program for residents of nursing facilities has been uneven among and within states.

- Implementation of the ombudsman program for residents of B&C homes has not been achieved in any significant way except in a small number of states.

- The ombudsman program activities of too many states are piecemeal, fragmented, and focused primarily on responding to complaints that relate to individual residents of nursing facilities. These states are not in compliance with the spirit of the program provisions as stated in the OAA; the Offices of the State LTC Ombudsman programs do not function as a whole, statewide, unified, integrated program delivering a range of individual, systemic, and educational efforts.

- AoA has not mandated any level of implementation for the legislated LTC ombudsman program, nor has the agency monitored the states' efforts at implementation. Although ombudsman programs vary in the amount of staff and volunteer resources being expended to serve the residents of LTC facilities, no agreed-upon level of effort exists to signify that an ombudsman program has been implemented at a minimum acceptable level in a state. States do not uniformly comply with the essential requirements for operating statewide ombudsman programs, and neither AoA nor any other federal agency employs mechanisms to require such compliance.

- AoA has not developed technical guidance materials that inform states of the federal government's operational definitions of a fully implemented Office of the State LTC Ombudsman program.

- Ombudsman programs need competent legal advice and backup, including, when the circumstances call for legal interventions, assistance to LTC facility residents in pursuing issues in the courts and in regulatory hearings. The availability of these services is extremely uneven across the country.

- Except in a very few states, SUAs have not fulfilled their responsibility to ensure that adequate and independent legal counsel is available to the ombudsman programs for the purpose of providing advice and counsel related to LTC residents.

Recommendations on Compliance

The committee considers the mission of the LTC ombudsman program to be worthy in purpose and deserving of support from public funds. Accordingly, the programs should operate throughout the country in compliance with federal mandates. The committee proposes eight recommendations as a result of this part of its review.³

3.1. **The committee recommends that Congress amend the Older Americans Act to allow state ombudsman programs to serve younger individuals who reside in long-term care facilities in which primarily elderly individuals reside. However, state ombudsman programs should strive to comply fully with their current mandates before using Older Americans Act resources to serve residents who are younger than 60 years of age. When applicable, the state long-term care ombudsman should coordinate activities and advocacy efforts with other organizations that serve as advocates for nonelderly residents.**

3.2. **The committee recommends that the Department of Veterans Affairs (VA) institute an agreement with the Administration on Aging (AoA) to ensure that long-term care ombudsman services are available to all veterans residing in nursing and domiciliary homes operated by the VA. The agreement should include the transfer of adequate funds from the VA to the AoA to support the provision of ombudsman services to VA-owned or VA-managed facilities.**

3.3. **The committee recommends that the Assistant Secretary for Aging develop and distribute a policy statement detailing the sanctions the AoA is authorized to use to enforce state compliance with statutory mandates of the long-term care ombudsman program. The statement should describe the sanctions and explain which conditions require or justify invoking each sanction.**

3.4. **The committee recommends that the Assistant Secretary for Aging issue clearly stated policy and program guidance that sets forth the federal government's expectations of state long-term care ombudsman programs. Such guidance should articulate operational principles in terms of basic elements of the program, including:**

³In this summary, recommendations are numbered to correspond to the numbering scheme used in the chapters in which they are found. For example, Recommendation 3.1 is the first recommendation that is made in Chapter 3.

- definitions, criteria, and standards to determine whether a state ombudsman program is operating as a unified entity throughout the state;
- designation and de-designation process(es) of all host agencies and all individual representatives within the ombudsman program;
- process(es) by which the state ombudsman program provides assistance (including training) to local ombudsman programs;
- method(s) by which the state ensures that its ombudsman program has suitable access to facilities, records, and residents;
- method(s) by which the state ensures that its ombudsman program provides meaningful annual reports; and
- method(s) by which the state ensures that adequate legal counsel is an integral part of the ombudsman program both in representing the ombudsman program itself and in providing advice and counsel in matters related to long-term care facility residents.

3.5. The committee recommends that Congress direct the Secretary of the Department of Health and Human Services to implement the statutory provisions set forth in Public Law 102-375 that require a federal Office of Long-Term Care Ombudsman Programs in the Administration on Aging and that Congress explicitly provide an adequate appropriation in the Older Americans Act for the position of Director of the Office of Long-Term Care Ombudsman Programs.

3.6. The committee recommends that the Assistant Secretary for Aging explicitly operationalize the federal government's responsibility for oversight of the long-term care ombudsman program. This should include (at a minimum) the following elements of program oversight: (1) active monitoring of programs by regional offices or the central office of the Administration on Aging; (2) effective technical assistance to the state programs; and (3) standards and procedures for training representatives of the Office of the State Long-Term Care Ombudsman.

3.7. The committee recommends that the Assistant Secretary for Aging develop plans of action and cooperative agreements with the Legal Services Corporation, the National Association of Protection and Advocacy Systems, the National Association of Medicaid Fraud Control Units, and the Office of the Inspector General of the Department of Health and Human Services to foster and encourage a variety of legal assistance resources for residents of long-term care facilities.

3.8. The committee recommends that the Assistant Secretary for Aging require that each state unit on aging include in its state plan a

description of how the state has funded and ensured the provision of adequate and independent legal counsel to the ombudsman program, including how all designated representatives of the Office of the State Long-Term Care Ombudsman are afforded legal counsel so that all their mandated duties and services can be and are performed.

CONFLICTS OF INTEREST

Legislative and Conceptual Aspects

The determination of whether actual or potential conflicts of interest in the administration and operation of the LTC ombudsman programs exist depends primarily on two factors: (1) the definition of or parameters describing occurrences of conflicts of interest and (2) the circumstances of the situation under review. Without a doubt, most state and local ombudsman programs are subject to one or more of the conflicts of interest reviewed by the committee.

Of particular concern to the committee is the prevalence of potential and real conflicts of interest that arise from the structural location of many of the Offices of the State LTC Ombudsman programs. Situations in which real, potential, and perceived conflicts of interest exist may be more prevalent than is typically understood, and perceived conflicts of interest may be as detrimental to operating the ombudsman program as real conflicts of interest. All conflicts of interest work to the disadvantage of the vulnerable client.

Ombudsmen-particularly state ombudsmen-operate in a politically charged environment accentuated by the fact that most often the state ombudsman is a state employee. Government cannot function efficiently if its employees work in opposing directions. All levels of government in the United States have formal and informal standards that govern chains of command. Every executive branch of government justifiably exercises some control over its employees' contacts with the legislative branch and media.

By federal statute, the ombudsman is required to speak out against government laws, regulations, policies, and actions when the circumstances justify such action. Taking such steps, however, is antithetical to the hierarchical rules of government. It is not surprising, therefore, that conflicts occur. The imposition of a state's routine chain-of-command rules on the ombudsman can significantly constrain his or her independence, although no person in such situations may intentionally act to interfere with the work of the ombudsman.

The committee began its review of conflicts of interest with the statutory provisions of the OAA that prohibit conflicts of interest in the LTC ombudsman programs. The parameters set forth in the act to identify situations of conflicts of interest are quite limited and outdated, focusing

almost exclusively on financial interests and nursing facility settings. They provide little guidance for addressing the conceptually related variations of conflict of interest—conflicts of loyalty, commitment, and control—that characterize the environments in which the ombudsman program operates in the 1990s.

The committee reviewed four major types of conflicts of interest: (1) organizational, (2) individual, (3) those arising from willful interference in the independent operation of the program, and (4) those related to the provision of legal counsel. Conflicts of interest can be dealt with either by prevention or by detection and correction. These are concepts and approaches similar to those in the quality-of-care field. Not all conflicts of interest can be prevented in the ombudsman programs, although prevention is clearly the preferred method of program administration and the most effective means of assuring compliance with the statutory provisions. Numerous mechanisms can ameliorate individual conflicts of interest, such as disclosure, ethical behavior, and accountability to the public.

Recommendations on Conflicts of Interest

The committee determined that conflict of interest problems are sufficient to warrant greater vigilance and a broader array of tactics to prevent, identify, and correct pertinent and significant conflicts. To that end, the committee offers four recommendations.

4.1. The committee recommends that Congress amend the Older Americans Act to include the following policy directive. By fiscal year 1998, no ombudsman program should be located in an entity of government (state or local) or agency outside government whose head is responsible for:

- licensure, certification, registration, or accreditation of long-term care residential facilities;
- provision of long-term care services, including Medicaid waiver programs;
- long-term care case management;
- reimbursement rate setting for long-term care services;
- adult protective services;
- Medicaid eligibility determination;
- preadmission screening for long-term care residential placements;

or

- decisions regarding admission of elderly individuals to residential facilities.

4.2. The committee recommends that the Assistant Secretary for Aging adopt a clear policy that prohibits parties who provide, purchase, or regulate services that are within the purview of the ombudsman program from membership on policy boards having governance over the long-term care ombudsman program. The policy should not prohibit these parties from membership on boards and councils that serve solely in advisory capacities.

4.3. The committee recommends that the Assistant Secretary for Aging establish procedures and resources by which to identify potential conflicts of interest in the areas of loyalty, commitment, and control that are pertinent to the long-term care ombudsman and ombudsman representatives and provide guidance on how to address such conflicts of interest.

4.4. The committee recommends that each state unit on aging, in exercising its responsibility to ensure that legal counsel is available without conflict of interest to the statewide long-term care ombudsman program, adopt the following three principles to guide the selection of counsel:

- For purposes of representing the ombudsman in (a) employment, contract, or other administrative functions and (b) litigation brought against the ombudsman in connection with the performance of his or her official duties, representation by the state's office of the attorney general is appropriate and generally free of conflict of interest.

- If advice and counsel related to the rights of long-term care facility residents is provided by a government-employed lawyer, then the lawyer and agency employing the lawyer, including any "umbrella" agency, should not advise or represent other agencies or interests that could conceivably have a conflict of interest with the resident's interests or ombudsman's responsibilities.

- If advice and counsel related to the rights of long-term care facility residents is provided by a lawyer not employed by the government, then the ombudsman should receive assurances of conformance to state rules of professional conduct for the legal profession.

EFFECTIVENESS OF THE OMBUDSMAN PROGRAM

The committee attempted to assess the effectiveness of the state LTC ombudsman program from several perspectives. The underlying impediment to sound assessment has been the lack of reliable and valid information that could be fit into any defensible **summative** evaluation format. For that reason, the committee opted for a formative evaluation effort—one that would highlight program issues, strengths, and weaknesses and would point to more specific questions deserving in-depth attention in coming years.

Continuance of the Ombudsman Program

On the basis of all the information it reviewed, collected, and analyzed, the committee concludes that the ombudsman program serves a vital public purpose. Every year the LTC ombudsman program helps many thousands of individual LTC facility residents, particularly those in nursing facilities, with a wide range of problems and concerns. The committee thus takes a strong supportive stance with respect to the ombudsman program. To underscore this commitment to the mission of the program:

5.1. The committee recommends that Congress continue the long-term care ombudsman program as set forth in the Older Americans Act.

Stating such a recommendation may seem superfluous from a group empaneled to examine a program that, on the face of it, serves a worthy cause and a needy population. However, the committee took seriously the question of whether the program merited continuation in its present form (or at all). Having concluded that it does, the committee intended, through the above recommendation, to make clear that the aims of those who crafted the original program and its subsequent modifications remain consequential today.

The LTC ombudsman program can justly claim to have improved the system of LTC services. Through systemic advocacy work and educational efforts, the state programs, individually and collaboratively, have brought to the attention of state and federal policymakers, regulatory agencies, and provider organizations a host of conditions that can and should be changed to improve the health, safety, rights, and welfare of LTC residents. Examples of changes advanced or promoted by ombudsman programs (often **in conjunction** with other organizations) include: enactment of the federal Nursing Home Reform Law of 1987 (in particular, provisions pertaining to quality of care and quality of life); increased personal needs allowances; protections from involuntary discharge and room transfers; reduced use of physical restraints;

improved building and safety standards; increased state funding for inspection and surveying of LTC facilities; reduced use of psychotropic medications; better licensing oversight of health care professionals; increased use of advance directives; stronger LTC staff competencies and sensitivities; and empowerment of residents through stronger resident and family governance structures.

In the B&C area, the ombudsman program has been partially implemented at best. Hence, evaluating national program effectiveness in this area is premature.

Exemplary Practices and Performance

The committee believes that the individual and systemic successes attributed to the ombudsman program occur despite considerable barriers in most, if not all, states. Obstacles to effective performance include inadequate funding, resulting staff shortages, low salary levels for paid staff, structural conflicts of interest that limit the ability to act, and uneven implementation among and within states. In many states, the program attempts to operate in a structural environment that expressly prohibits or, at least, does not foster its ability to carry out all federally mandated functions. The committee observed such examples as prohibitions on state and local ombudsmen from talking with any state or federal legislators about issues of concern to residents and ombudsmen who attempted to carry out additional and conflicting roles such as adult protective services officials.

As a consequence of what it perceived to be the significant drawbacks of this variation in basic program implementation and practice, the committee has developed a detailed scheme relating to the structure and activities of the program called “Elements of **Infrastructure** and Functions.” The elements are expressed in terms of exemplary, essential, and unacceptable practices. They incorporate prerequisites for effective ombudsman program performance. The detailed elements and respective practice levels are found in tables in Chapter 5 of the committee’s report. They include the following categories:

- Structure of the Office of the State LTC Ombudsman and Elements of the Host Agency(s) for the State and Local Entities;
- Qualifications of Representatives of the Office;
- Legal Authority;
- Resources (financial, information management, legal, and human);
- Office of the State LTC Ombudsman Program;
- Individual Resident Advocacy Services;
- Systemic Advocacy Work; and
- Educational Services.

Committee members underscored their belief in the value of building upon these “ideal types” of practices as a basis for objectively measuring compliance with the legislative mandate. In addition, the exemplary practices offer a standard and a challenge for ombudsman programs in terms of higher levels of effectiveness and service. Thus:

5.2. The committee recommends that the Administration on Aging build upon the committee’s proposed set of exemplary, essential, and unacceptable practices to develop and implement an objective method to assess compliance of state long-term care ombudsman programs.

Data and Information Systems

As noted above, because the ombudsman program is still developing and evolving, and because data on program performance are not available, evaluating the program’s effectiveness in any comprehensive way is not possible. Other barriers to adequate assessment also exist. Agreement has been lacking about the definition of goals. Implementation has been extremely varied, in part because of broad and uneven interpretations of the OAA mandate. No formal evaluation component was ever built into the program. Finally, only recently has AoA adopted a standardized data reporting system of any complexity.

Of all these issues, the committee focused on information systems as an area that AoA could and should remedy. Accordingly, the committee developed a set of recommendations in this area.

5.3. Building on work already begun by the Administration on Aging and the National Association of State Long-Term Care Ombudsman Programs, the committee recommends that the Secretary and Assistant Secretary for Aging, Department of Health and Human Services, establish and implement an information system for the ombudsman program that provides an empirical basis for:

- evaluating and improving complaint resolution efforts by identifying the extent to which ombudsmen have been effective in resolving complaints and issues to residents’ satisfaction;
 - identifying more precisely the kinds of problems (resolved or not) that affect the lives of residents of nursing and residential care facilities in order to provide a basis for systemic advocacy and change;
 - documenting the key efforts made toward systemic advocacy and the results of those efforts to address priority long-term care issues; and
-

- **documenting and analyzing the full range of activities of the long-term care ombudsman programs.**

To follow up this overall recommendation about information systems for the ombudsman program, and reflecting its concern about the paucity of comprehensive and accurate data to assess program activities and performance, the committee concluded that additional, more specific, or more technical points should be made with respect to data and information systems. Two recommendations pertaining to these point are as follows:

5.4. The committee recommends that the Assistant Secretary for Aging continue the efforts of the Administration on Aging to develop, refine, and implement a uniform data collection and reporting system. The committee recommends, at a minimum, that the data system should:

- **be based on a manageable number of uniform and reliable data items-each of which has precisely specified, field-tested definitions;**
 - **be derived from annual statistical reports submitted by state long-term care ombudsman offices that provide information in terms of the data items in the previous point;**
 - **include a clear indication of status of complaint resolution from a consumer perspective;**
 - **be used to provide feedback to state and local ombudsman programs;**
 - **be available for public use to foster research and inform decision making;**
 - **incorporate methods and procedures for continuous revision and improvement; and**
 - **be reviewed and updated no less than once every three years.**

5.5. The committee recommends that the Assistant Secretary for Aging periodically conduct audits of the data collection and reporting systems of state ombudsman programs to ensure that all states adhere to the national standards of the uniform data collection and reporting system.

The committee underscored the importance of well-defined, accurately reported, uniform data in which each item has precisely the same meaning for all state programs. Committee discussion emphasized the necessity of assuring that the burden of reporting is minimized and realistic, given the facts that staff resources are limited and that volunteers are crucial in data collection efforts. Time spent recording data is time not available for direct service. Thus, all items intended for a formal data collection instrument should be carefully

examined and included only if they have demonstrated utility for AoA or state or local ombudsman programs (or, ideally, both). Preference should be given to items that are useful in documenting the nature and outcomes of the full range of ombudsman services. Committee members expressed particular interest in the value of all state ombudsmen offices commenting consistently on four specific elements of information, as noted in this recommendation:

5.6. The committee recommends that the Secretary and Assistant Secretary for Aging, Department of Health and Human Services, require that each Office of the State Long-Term Care Ombudsman include in its annual report, in addition to currently required elements, information on and comments about:

- the level of awareness of residents, their agents, and other parties regarding the ombudsman program, and the availability of ombudsmen to individual residents;
- the extent to which the complaints and concerns of residents have been satisfactorily resolved;
- the extent to which ombudsmen have provided input into activities designed to improve the overall system of care and services for long-term care residents; and
- the extent to which ombudsmen have improved the overall system of care and services for long-term care residents.

Research Imperatives

Almost no evidence exists that causally links the activities and the outcomes of the ombudsman program. For example, little, if any, empirical information relates participation in nursing facility surveys or development of an annual report with such outcomes as changes in LTC facility practices that show more respect for residents' rights or revisions in state or federal laws that provide legislative backing for residents' rights. Just as research is being conducted to assess linkages among processes, structures, and outcomes in various aspects of the U.S. health care system, so too the need exists for such research relating to the LTC ombudsman program. To this purpose, the committee offers the following recommendation:

5.7. The committee recommends that the Administration on Aging, the Health Care Financing Administration, the Agency for Health Care Policy and Research, other government agencies, and foundations support research to develop valid and reliable measures for assessing the impact

of ombudsman activities on outcomes relative to the well-being of residents of long-term care facilities, at both individual and systemic advocacy levels.

Adequate Management of Volunteers

A prerequisite to effectiveness is adequate resources. Paid staff is the most crucial of all resources. To ensure that capacity exists for an effective program, staffing issues must be addressed for each state LTC ombudsman program, quite apart from funding issues. Based on site visits and other data gathered and analyzed, the committee agreed that staffing resources were minimal to inadequate from a national perspective.

The committee was particularly interested in information that suggests that many of the more “successful” programs make good use of a large number of volunteers. Use of ombudsman volunteers is positively associated with routine visitation and number of complaints made and resolved. This fact calls attention to the importance of recruiting, training, and retaining volunteers and to their singular contributions to the adequate functioning and performance of the program. Volunteers can provide a level of authenticity and consumer “grassroots” participation that is lacking in most other systems designed to protect and support the frail elderly. The continued use of well-trained volunteers is very much in keeping with the original intent and design of the program.

The committee concluded that the establishment of a standard staff-to-volunteer ratio was needed to protect and manage this resource. Thus, in setting the standard recommended here, the span of management of individuals was emphasized rather than the quantity of effort provided per volunteer (i.e., hours volunteered). The committee suggests a minimum standard for this staff-to-volunteer ratio of 1:40. It strongly encourages state LTC ombudsman programs that involve volunteers to maintain paid staff-volunteer ratios at the more robust level of 1:20.

5.8. The committee recommends that the Assistant Secretary for Aging establish a standard for ensuring the adequate management of volunteers who serve as designated ombudsmen. The committee suggests that the ratio of staff to volunteers be in the range of 1 paid full-time equivalent manager for every 20 to 40 volunteers.

ADEQUACY OF RESOURCES

Financial Resources and Program Performance

The full intent of Congress with respect to the LTC ombudsman program has not been met in all—indeed, perhaps not in **any**—state of the union. Some states fall short in not having expanded to B&C homes, other states do not have adequate cycles of visitation for all LTC facilities, some states operate fragmented programs and individual advocacy efforts that have no link to preventive or educational system efforts, and still others lack appropriate access to legal services.

Many factors compromise the fulfillment of congressional-and **public**—expectations. A significant factor is the overriding realities of budget shortfalls and inequitable resource allocations. At the heart of many of the problems lie deficiencies of financial resources rather than any lack of interest or basic commitment to the LTC ombudsman program or LTC facilities. In addressing the subject of adequacy of resources, the committee confined its discussions to resources for bringing the program into full implementation and compliance with today's statutory mandate for nursing facilities and B&C homes. It did not attempt to forecast the level or type of resources that might be needed to fulfill any possible expansion of the program (with respect to LTC, to the elderly, or to the nation as a whole secondary to comprehensive health care reform).

The committee approached the question of whether federal and other resources supporting the LTC ombudsman programs were adequate by identifying, first, some proxy measures of performance and, second, some levels of effort that link to resources. Its analysis included a review of such factors as the number of FTE paid staff per number of LTC beds, peer nominations of successful programs, and visibility. The available data, however, does not indicate that a straightforward relationship exists between staffing relative to LTC beds and the fulfillment of the duties of the ombudsman program.

By triangulating on data from several sources, the committee arrived at the conclusion that resources are not adequate for each state LTC ombudsman program to perform at a level that ensures compliance with even the basic, decade-old mandates of the OAA ombudsman program. In the committee's judgment, 1 FTE paid staff per 2,000 LTC beds is an essential resource standard, and it provides a measure against which the adequacy of resources can be judged. The committee concludes that, at a minimum, additional resources are needed to support an increase of about 300 FTE paid staff. Using the FY 1993 average national program expenditure of approximately \$43,240 per FTE paid staff supports the argument for an increase of \$13.2

million beyond FY 1993 total spending. If the current distribution of resources remains the same, then federal sources would have to supply approximately \$8.8 million in new dollars; state and local sources would have to supply \$4.4 million. In the committee's view, therefore, a federal appropriation within five years of about \$32.5 million (\$23.7 million plus \$8.8 million) is a defensible target. Assuming an inflation rate of 4 percent per year, estimates yield a target figure for FY 1998 of approximately \$39.5 million in federal funds.

6.1. The committee recommends that by fiscal year 1998 Congress increase the appropriations through Title VII, Chapter 2 of the Older Americans Act for the state long-term care ombudsman programs to an amount that ensures that all state Offices of the Long-Term Care Ombudsman program are funded at a level that would permit them to perform their current functions adequately. The committee further recommends that the factor of 1 full-time equivalent paid staff working as an authorized, designated ombudsman per 2,000 long-term care beds be used as a base indicator of performance and a unit of effort to determine the amount of additional resources needed.

The committee recognizes that further analysis is needed to determine more accurately the level of additional funding needed at the national level to bring each state up to a minimum level of resources.

Formula for Allocating Federal Funds and Level of State Contributions

The committee recognizes the need to distribute federal funds to states in a **manner** that more rationally considers the "beneficiaries" of the ombudsman programs—that is, the elderly residents of LTC facilities—and to that purpose it recommends that the distribution formula for Title VII-2 funds be changed. The formula for allocating federal funds under Title VII-2 of the OAA is based on total numbers of persons age 60 and older. This formula has several drawbacks from the perspective of need and equity in the context of the ombudsman program's mission. For example, states vary in the ratio of LTC beds to population 60 years of age and older, and some states with a high percentage of the nation's population in that age range have a low percentage of the nation's LTC beds.

Thus, in addition to arguing for a meaningful increase in federal appropriations for the ombudsman program, the committee has concluded that the major drawbacks of the current state-by-state allocation strategy must be addressed. Accordingly:

6.2. The committee recommends that Congress revise the interstate formula for allocating funds under Title VII, Chapter 2 of the Older Americans Act and further recommends that Congress give consideration to equitably distributing funds on the basis of such factors as the number, size, and type of long-term care facilities in each state and wage and cost-of-living indices.

At present, state monetary matching is not required for federal dollars appropriated under Title VII of the OAA, as it is under Title III-B. This is a major inconsistency within even a single program. Moreover, it is one that may permit states to avoid giving the program its intended level of support, in particular if increases are made in federal appropriations through Title VII-2, as is recommended by the committee.

According to the committee, state and local governments and entities have a responsibility to provide significant financial support to the program. The committee did not examine the details of a required percentage match, in either theoretical or practical terms. It did, however, agree that a match of no less than 20 percent of federal funds would be a defensible minimum.

6.3. The committee recommends that Congress require that states match the federal funding they receive under Title VII, Chapter 2 of the Older Americans Act appropriations for the long-term care ombudsman programs and that the state match should be no less than 20 percent.

Management of Fiscal Resources

The committee makes two recommendations to enhance the management of fiscal resources. The committee believes that state ombudsman offices should have unrestricted knowledge of their own budgets and, within the boundaries permitted by state budget policy and procedures and required by federal mandates for compliance, decision making-authority among line-item expenditures. Host agencies should exercise prudent judgment regarding the use of ombudsman service monies to support administrative costs.

The committee recognizes that contracting and host agencies may need to use ombudsman program funds to offset some administrative costs. For the most part, according to information available, local host agencies tend to provide additional resources to the ombudsman programs rather than the other way around. During this study, however, the committee became concerned about the possibility that in some locales a series of host agencies may be assessing administrative charges against the earmarked ombudsman program budget to a degree that severely limits the ability of the ombudsman and

designated representatives to deliver services. This practice becomes especially burdensome when the budget of a local ombudsman program administratively moves through two or more levels of host or contracting agencies, each of which assesses a fee against the ombudsman's budget.

6.4. **The committee recommends that the Assistant Secretary for Aging issue program guidance to states that stresses the importance of delegating to the Office of the State Long-Term Care Ombudsman responsibility for managing all of the human and fiscal resources earmarked for the state ombudsman program within the boundaries of what is permitted by state budget policy and procedures and required by federal mandates for compliance. The Office of the State Long-Term Care Ombudsman program should in turn work with local ombudsman programs and their host agencies to assign fiscal management responsibility to appropriate managers.**

6.5. **The committee recommends that Congress direct the Office of the Inspector General, Department of Health and Human Services, to conduct an audit across the states of expenditure practices in the ombudsman programs to determine the extent of diversion of ombudsman program funds for administration and indirect costs and its relation to multiple sponsoring agencies. Congress should subsequently review the audit's findings to determine whether congressional or administrative action is needed to prevent excessive use of ombudsman program resources for host agencies' administrative costs.**

Unmet Need and Unfunded Responsibilities

The committee's report discussed the question of "unmet need"—that is, the expectations that Congress, the elderly community, and others have for the ombudsman program, which frequently go beyond the present tasks assigned through the OAA. In fact, unmet need is not confined to possible or future program mandates; it exists today in the majority of states with respect to noncompliance of their ombudsman programs in serving residents of B&C homes. Inherent in the ombudsman's advocacy role are a plethora of strategies not being consistently addressed, including interagency rapport, involvement with other community LTC and advocacy programs, administrative advocacy, and legislative lobbying—all for the purpose of influencing the care and well-being of LTC residents aged 60 and older.

With respect to adequacy of funding, the committee concludes that the present level of support for the ombudsman program is completely insufficient to allow it to expand to satisfy these unmet needs. The committee asserts

unequivocally that the first priority is that the program be provided with resources commensurate with meeting all the current mandates, including those that have existed, but been neglected, since 1981. That position underlies the thrust of earlier recommendations about federal funding, the allocation formula for that funding, and the state match.

If, however, Congress or others determine that expansion of the program beyond its present mandates is desirable, then the committee wishes to go on record with respect to the fiscal realities of that movement. Specifically:

6.6. The committee recommends that, if Congress mandates additional responsibilities for the ombudsman programs, then Congress should also provide adequate additional appropriations to the ombudsman program.

NEED FOR AND FEASIBILITY OF EXPANDING THE OMBUDSMAN PROGRAM

The committee accepts the conventional wisdom that self-advocacy by consumers is the most desirable solution to many of the problems consumers face. Further, the committee also acknowledges that frail elderly people receiving health care and LTC services, ranging from skilled home health care to the wide range of in-home services funded under home- and community-based waivers and state-funded programs, may be vulnerable to neglect, abuse, and poor care. Such consumers of health care and LTC services, especially persons who **cannot** advocate for themselves when confronted by systems that are complex, fragmented, and cost-conscious, need an independent intermediary and advocate. Such advocates do exist in some places and in some capacities, but they cannot always act expressly on behalf of the consumer, provide both individual and systemic advocacy, or work preventively.

The 13 states that have expanded ombudsman services to health care and LTC consumers outside of LTC residential facilities have gained limited experience to date. The committee heard testimony that this circumstance arises, in large measure, from inadequate resources to implement and operate a fully viable program. The result, however, is that little empirical evidence is available to support decision making on whether and how the current ombudsman program ought to be expanded.

On the basis of what is already known, most committee members believe that some entity or individual—whether or not it is the current LTC ombudsman—is needed to answer questions, to provide systemic advocacy, and to intervene in problem situations for some consumers.

Other activities are in place ostensibly to help address the needs and interests of vulnerable people receiving community health and LTC services. These include: case management programs; the Adult Protective Services efforts available in most states; the home care complaint hotlines mandated by law in 1987, which have been variably implemented across the United States; and licensure, certification, and survey processes for home health agencies. In addition, public and private guardianship and conservatorship policies are meant to ensure that those unable to make decisions have an agent to act in their best interests. All these mechanisms have strengths and limitations. It is unclear, therefore, whether the solution to these problems is to strengthen one or more of the existing mechanisms, combine and strengthen advocacy functions into a new structure, or create an ombudsman as a superordinate, general operation.

Various arguments are marshalled for and against expanding the current LTC ombudsman program to other settings, as a means of helping to fill deficits in the present system by which people receive health care and LTC services. Opponents raise both jurisdictional and operational points. Given the status of the current program, the various philosophical and operational considerations highlighted above, and the general lack of persuasive evidence on any side, the committee takes a cautious stance about expansion. Specifically:

7.1. The committee recommends that, before any consideration is given by a state to expand its long-term care ombudsman program to serve individuals other than those mandated by the Older Americans Act, the Offices of the State Long-Term Care Ombudsman programs that are supported with Older Americans Act funds fully implement existing mandates for serving older residents of long-term care facilities.

This recommendation is intended to underscore the need to fulfill existing mandates before taking on added duties, regardless of how worthwhile they may be. The committee favors improving the operation of the current ombudsman program so that it provides a stronger base for any future expansion. Thus, the committee reemphasizes here the strong recommendations it has made about funding, program evaluation, and similar topics.

Nevertheless, the committee believes that some interim steps may be taken to clarify further the desirability and feasibility of expansion. To that end:

7.2. **The committee recommends that Congress, through the Secretary of the Department of Health and Human Services, direct the leadership of the Administration on Aging, the Agency for Health Care Policy and Research, the Administration on Developmental Disabilities,**

and the Health Care Financing Administration to develop and support research and demonstration initiatives to determine how ombudsman advocacy services can best be delivered for consumers of health care and long-term care services. Because of the potentially significant role ombudsmen may have in ensuring quality of care in a reformed health care system, the committee also recommends that Congress require that the Secretary undertake these initiatives during fiscal years 1996-1999 and submit the accumulated results of such research to the Congress no later than January 1, 2000.

CLOSING COMMENTS

During its meetings, the committee conjectured about how a future LTC system might be configured and about the trends that might affect both the need for and nature of the ombudsman program. Consensus on these topics was neither desired nor sought. Based on all this input and its own deliberations, the committee concluded that rather substantial changes in the very nature of LTC are likely in the next decade; it also judged that any ombudsman program will face challenges to adapt and be responsive to changing needs.

If the committee's recommendations are adopted-including those related to increasing funding, minimizing conflict of interest, developing and enforcing program compliance, and enhancing the capacity of the ombudsman program to generate information about its activities and their effects-then policymakers should be in a better position 10 years from now to make decisions about the desirable evolution of an ombudsman program to meet future needs for advocacy in whatever kind of health care system has emerged in the meantime.
